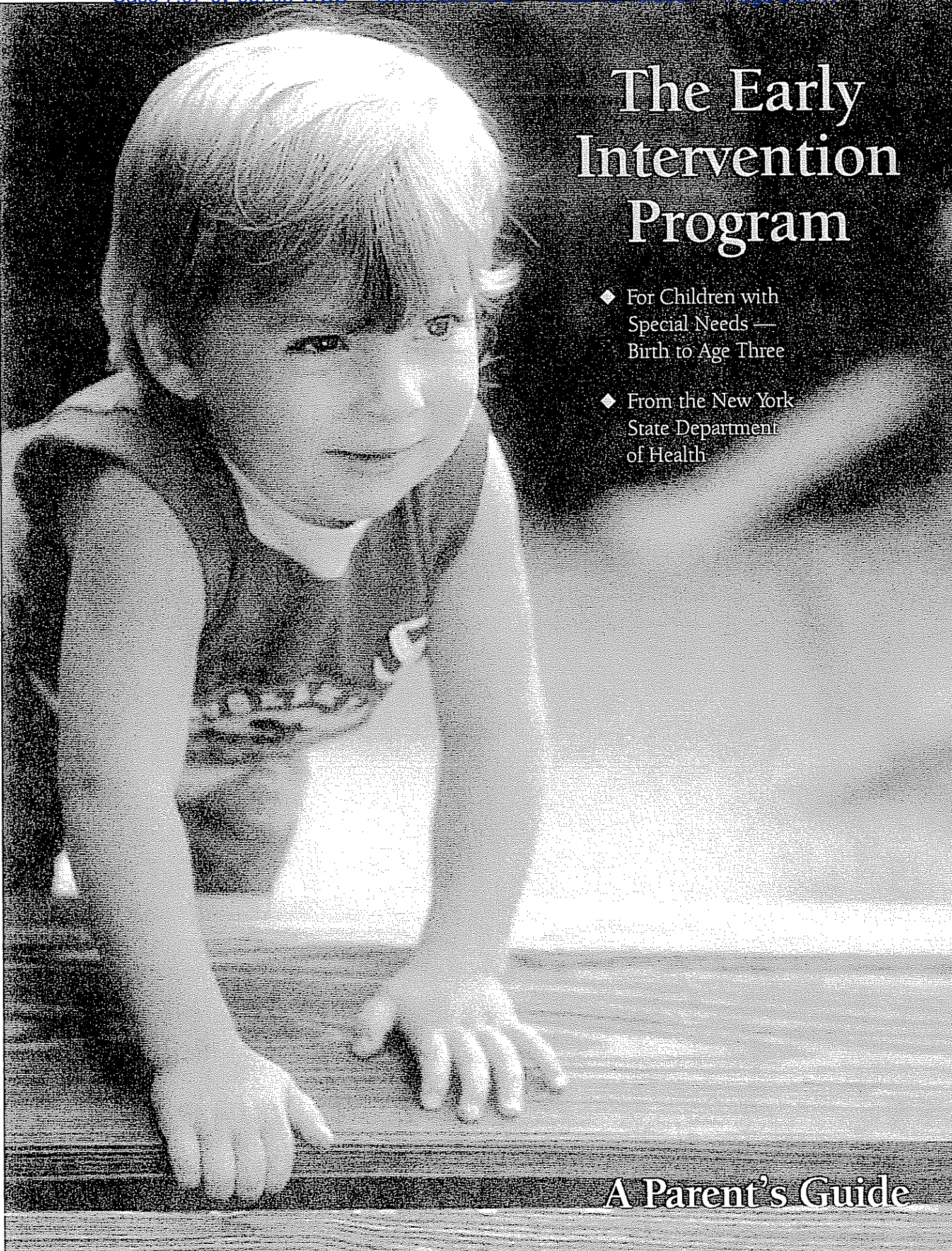


EXHIBIT “L”



The Early Intervention Program

- ◆ For Children with
Special Needs —
Birth to Age Three
- ◆ From the New York
State Department
of Health

A Parent's Guide



STATE OF NEW YORK

GEORGE E. PATAKI
GOVERNOR

Dear New York family,

Having a young child with special needs presents a unique challenge for families. Your child may need extra help and attention when learning new skills. You may have to learn new ways of caring for him or her. And your whole family may need support in adjusting to the new demands placed on them.

Since 1993, New York State's Early Intervention Program has been helping families find home and community-based services for children with special needs. Early Intervention is a partnership on several levels: between state and local government agencies who work to identify and evaluate children who would benefit from developmental services; and county agencies, health care providers, and parents who plan and provide the services. Since its inception, the New York State early intervention system has provided services to thousands of children and families.

If your child is being considered for Early Intervention services, this Parent's Guide will help you learn how the program works and what rights and responsibilities you have as a parent. It also gives you phone numbers to call for more information, samples of the kinds of letters you may need to write, and definitions of terms you will hear. I hope it will help you and your child get the most out of the Early Intervention Program.

With all good wishes,

A handwritten signature in black ink that reads "George E. Pataki". The signature is written in a cursive style.

George E. Pataki
Governor



Welcome to the Early Intervention Program

The early years of a child's life are very important. During the infant and toddler years, children grow quickly and have so much to learn. Some children and families face special challenges and need extra help. Early help *does* make a difference!

The Early Intervention Program is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help you and your family:

- Learn the best ways to care for your child.
- Support and promote your child's development.
- Include your child in your family and community life.

Early Intervention services can be provided anywhere in the community, including:

- Your home.
- Your child care center or family day care home.
- Recreational centers, play groups, playgrounds, libraries, or any place parents and children go for fun and support.
- Early childhood programs and centers.



As a parent, you help decide:

- What early intervention services your child and family need.
- The outcomes of early intervention that are important for your child and family.
- When and where your child and family will get early intervention services.
- Who will provide services to your child and family.

You are the most important person in your child's life. You know your child best. You understand your child's needs, and what is helpful and what is not. You have the most information about – and responsibility for – your child's growth and development. In a world of professional titles, consider yourself a **FAMILY INFORMATION SPECIALIST!**

If you think the Early Intervention Program can help you and your child, there are six steps to follow. *A Parent's Guide to the Early Intervention Program* starts by telling you about some of the basic facts about the Early Intervention Program. Then, *A Parent's Guide* explains each step to follow—and gives you tips on how to make early intervention work best for your child and family.

You are an important person in the Early Intervention Program. This is *your* book—it was written for parents, with the help of parents. We hope it will make your job as a parent a little easier!

Important Contact Information

For more information about the Early Intervention Program and its services, contact:

Bureau of Early Intervention
Division of Family Health
New York State Department of Health
Corning Tower, Room 287
Albany, New York 12237-0660
518-473-7016
518-486-1090 (FAX)
Email: eip@health.state.ny.us
www.health.state.ny.us/nysdoh/eip/index.htm

For more information about early intervention, local phone numbers for your county Early Intervention Program, and other child-related services, contact:

“Growing Up Healthy” 24-Hour Hotline
1-800-522-5006
In New York City—311

New York Parent's Connection
1-800-345-KIDS (5437)
(available Mon-Fri 9am – 5pm)

Early Childhood Direction Centers (See page 35 for description)
New York State Education Department
518-486-7462
518-474-5652-TTY
www.vesid.nysed.gov/specialed/transition/whocan.htm



Parent to Parent of New York State
(See page 35 for description)
518-381-4350
1-800-305-8817
www.parenttoparentnys.org

Parent Training and Information Centers
(See page 35 for description)
www.taalliance.org/PTIs.htm

- Statewide (Except NYC)
585-546-1700
1-800-650-4967 (New York State Only)
www.advocacycenter.com
- In New York City
212-947-9779
www.advocatesforchildren.org
212-677-4650
www.resourcesnyc.org
- Advocacy Services
(See page 35 for description)
1-800-624-4143
www.cqc.state.ny.us

First, the Basics...

Your Early Intervention Official (EIO)

In New York State, all counties and the City of New York are required by public health law to appoint a public official as their Early Intervention Official.

Get to know your Early Intervention Official. She or he will be an important person in your child's and family's early intervention experience!

Your Early Intervention Official is the person in your county responsible for:

- Finding eligible children.
- Making sure eligible children have a multidisciplinary evaluation.
- Appointing an *initial service coordinator* to help families with their child's *multidisciplinary evaluation* and *Individualized Family Service Plan (IFSP)*.
- Making sure children and families get the early intervention services in their IFSPs.
- *Safeguarding* child and family rights under the Early Intervention Program.

The Early Intervention Official is the “*single point of entry*” for children into the Early Intervention Program. This means that all children under three years of age who may need early intervention services must be referred to the Early Intervention Official. In practice, Early Intervention Officials have staff who are assigned to take child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official (see page 9, “Step 1: Referral”). Sometimes, someone else will be the first to raise



a concern about a child's development. New York State public health law requires certain professionals to refer infants and toddlers to the Early Intervention Official if a problem with development is suspected. However, no professional can refer a child to the Early Intervention Official if the child's parent says no to the referral.

Your Service Coordinator

Your service coordinator is your key to early intervention services!

There are two types of service coordinators in New York State – an *initial service coordinator* and an *ongoing service coordinator*.

Your *initial service coordinator* will be appointed to you by your Early Intervention Official. Your initial service coordinator will help you with all the steps necessary to get services – from your child's multidisciplinary evaluation to your first Individualized Family Service Plan (IFSP).

You will be asked to choose your *ongoing service coordinator* as part of your first IFSP. The main job of your ongoing service coordinator is to make sure

New York State's definition of developmental delay

Developmental delay means that a child has not attained developmental milestones expected for the child's age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social-emotional, or adaptive development.

For the purposes of the Early Intervention Program, a developmental delay is a delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures, and/or instruments, and documented as:

- A 12-month delay in one functional area; or
- A 33% delay in one functional area or a 25% delay in each of two areas; or
- If appropriate, standardized instruments are individually administered in the evaluation, a score of at least 2.0 standard deviation below the mean in one functional area or a score of at least 1.5 standard deviation below the mean in each of two functional areas.



you and your child get the services in your IFSP. Your ongoing service coordinator will also help you change your IFSP when you need to and make sure your IFSP is reviewed on a regular basis.

You can keep your initial service coordinator – or you can choose a new person to be your ongoing service coordinator. Later in this book, you'll find some tips to help you with this choice.

Who is eligible for the Early Intervention Program?

Children are eligible for the Early Intervention Program if they are under three years old AND have a disability OR developmental delay. A disability means that a child has a *diagnosed physical or mental condition* that often leads to problems in development (such as Down syndrome, autism, cerebral palsy, vision impairment, hearing impairment). A developmental delay means that a child is behind in at least one area of development, including:

- Physical development (growth, gross and fine motor abilities).
- Cognitive development (learning and thinking).

- Communication (understanding and using words).
- Social-emotional development (relating to others).
- Adaptive development (self-help skills, such as feeding).

Your child does not need to be a U.S. citizen to be eligible for services. And, there is no income “test” for the program. You and your child do have to be residents of New York State to participate in the Early Intervention Program.

How is eligibility decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to find out if they are eligible for services. The multidisciplinary evaluation will also help you to better understand your child’s strengths and needs and how early intervention can help.

A child who is referred because of a diagnosed condition that often leads to developmental delay – like Down syndrome – will always be eligible for early intervention services. If your child has a diagnosed condition, your child will still need a multidisciplinary evaluation to help plan for services.

If your child has a delay in development – and no diagnosed condition – the multidisciplinary evaluation is needed to find out if your child is eligible for the Early Intervention Program. Your child’s development will be measured according to the “*definition of developmental delay*” set by New York State.

What services are available?

The Early Intervention Program offers many types of early intervention services. Early intervention services are services that are:

- Aimed at meeting children’s developmental needs and helping parents take care of their children.

What is an Individualized Family Service Plan (IFSP)?

An IFSP is a written plan for the early intervention services you and your child will get from the Early Intervention Program. Your IFSP will:

- Include the outcomes for your child and family – what you and your family hope to gain from early intervention services.
- Describe the early intervention services your child and family will get to help you reach your outcomes.
- Describe who will provide services and where, when, and how often.
- Give the ways services will be used to help you and your family reach those outcomes.



Respite services

What is respite?

Respite is temporary care of a child with a disability, given to provide relief to the family. Sometimes, the demands of caring for an infant or toddler with disabilities are overwhelming. Respite can help reduce family stress. Some families use respite services to keep appointments, run errands, spend time with other children and family members, or just relax.

How can I get respite services?

You can ask for respite as part of your Individualized Family Service Plan. Some factors that weigh into decisions about respite are:

- Severity of a child's disability and needs.
- A child's risk of out-of-home placement.
- Lack of other supports to the family.
- Stressful family situations.
- The need for respite expressed by parents.

- Included in an Individualized Family Service Plan (IFSP) agreed to by the parent and the Early Intervention Official.

Here's a list:

- Assistive technology services and devices.
- Audiology.
- Family training, counseling, home visits, and parent support groups.
- Medical services *only for diagnostic or evaluation purposes*.
- Nursing services.
- Nutrition services.

- Occupational therapy.
- Physical therapy.
- Psychological services.
- Service coordination services.
- Social work services.
- Special instruction.
- Speech-language pathology.
- Vision services.
- Health services *needed for your child to benefit from other early intervention services*.
- Transportation to and from early intervention services.

How are Early Intervention services provided?

Only *qualified* professionals—individuals who are licensed, certified, or registered in their discipline and approved by the State—can deliver early intervention services. All early intervention services can be given using any of the following service models:

- *Home- and community-based visits.* In this model, services are given to a child and/or parent or other family member or caregiver at home or in the community (such as a relative's home, child care center, family day care home, play group, library story hour, or other places parents go with their children).
- *Facility or center-based visits.* In this model, services are given to a child and/or parent or other family member or caregiver where the service provider works (such as an office, a hospital, a clinic, or early intervention center).
- *Parent-child groups.* In this model, *parents and children get services together* in a group led by a service provider. A parent-child group can happen *anywhere* in the community.
- *Family support groups.* In this model, parents, grandparents, siblings, or other relatives of the



child get together in a group led by a service provider for help and support and to share concerns and information.

- *Group developmental intervention.* In this model, children receive services in a group setting led by a service provider or providers *without parents or caregivers*. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and can happen *anywhere* in the community.

Do I need to worry about costs?

No! If your child is eligible for the Early Intervention Program, early intervention services must be provided *at no cost to you*.

Health insurance, including private insurance and Medicaid, is used to pay for early intervention services in New York State.

New York State law protects family insurance policies from being affected by payments for early intervention services. Your insurance policy can only be used if your insurance company is licensed or regulated by New York State. If your policy is *not* subject to New York State regulation, *its use is voluntary* on your part.

When your insurance is used for early intervention:

- You will *not* have to make out-of-pocket payments for co-payments or deductibles. This is true even if your insurance company is not licensed or regulated by New York State and you *volunteer* to use your insurance for early intervention.
- Payments for early intervention services will *not* be applied to the annual and lifetime caps in your insurance policy. Your coverage for health services will not be reduced because your child is receiving early intervention services. These *protections apply to your policy only if your insurer is licensed or regulated by New York State*.

New York State has a health insurance plan for kids called Child Health Plus. Children under the age of 19 who are not eligible for Medicaid and who have limited or no health insurance may be eligible. For information, call the Child Health Plus toll-free number at 1-800-698-4KIDS (1-800-698-4543).

What are my rights and responsibilities as a parent in the Early Intervention Program?

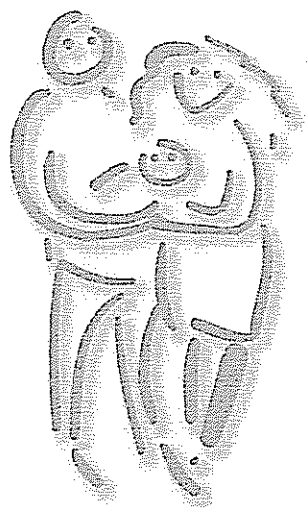
As a parent in the Early Intervention Program:

- You take part in all the decisions.
- Meetings are held at times good for you.
- Your permission is required at every step of the process.
- All information about your child and family is confidential.
- You have the right to have your views heard and considered if you disagree with others.

To learn more about your rights, and what to do if you disagree with any decision, see "Your Rights as a Parent in the Early Intervention Program" on page 26 of this book.

Early Intervention Steps

Family Concern



1. Referral *(unless parent objects)*

- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program
- Child referred to EIO within 2 days of identification
- Early Intervention Official assigns Initial Service Coordinator



2. Initial Service Coordinator

- Provide information about EIP
- Inform family of rights
- Review list of evaluators
- Obtain insurance/Medicaid information
- Obtain other relevant information



4. The IFSP Meeting*

(if child is eligible)

- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
- Family and EIO agree to IFSP
- Identify Ongoing Service Coordinator
- EIO obtains social security number(s)

3. Evaluation*

- Determine eligibility
- Family assessment, optional
- Gather information for IFSP
- Summary and report submitted prior to IFSP



Early Intervention Services*

- assistive technology devices and services
- audiology
- family training, counseling, home visits and parent support groups
- medical services only for diagnostic or evaluation purposes
- nursing services
- nutrition services
- occupational therapy
- physical therapy
- psychological services
- service coordination
- social work services
- special instruction
- speech-language pathology
- vision services
- health services
- transportation and related costs

Areas of Development

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development

* May access due process procedures

5. IFSP—Review Six Months/ Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies, and/or services
- If parent requests, may review sooner:
 - If parent requests an increase in services, EIO may ask for independent evaluation



6. Transition

- Plan for transition included in IFSP
- Transition to:
 - services under Section 4410 of Education Law (3-5 system)
- OR
- other early childhood services, as needed



Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.

Revised 12/04

Step 1: Referral

Your first step into the Early Intervention Program begins with your child's referral to your Early Intervention Official (EIO). Professionals must refer babies and toddlers to the Early Intervention Official – unless the parent says no – when there is a concern about child development. As a parent, you can also refer your child to your Early Intervention Official if you suspect a problem. If you have this book, chances are your child has already been referred to your Early Intervention Official. If you do need to make a referral you can:

1. Contact your Early Intervention Official (see sample letter on page 36), or call 1-800-522-5006; in New York City—311.
2. Talk with your doctor or someone else you trust and ask them to help you with the referral.

The referral process helps you learn about the Early Intervention Program. You must decide if early intervention makes sense for you and your child. You must give your permission to have your child evaluated for the program and to receive services.



Referral

When a professional refers a child to the EIP, he or she must:

- Tell parents about services available and how services may help.
- Inform parents that the child will be referred – unless the parents say no to the referral.
- Inform parents about the referral in the language they use, whenever possible.
- Make sure all information given to the EIO is kept confidential.

Step 2: Meeting Your Initial Service Coordinator

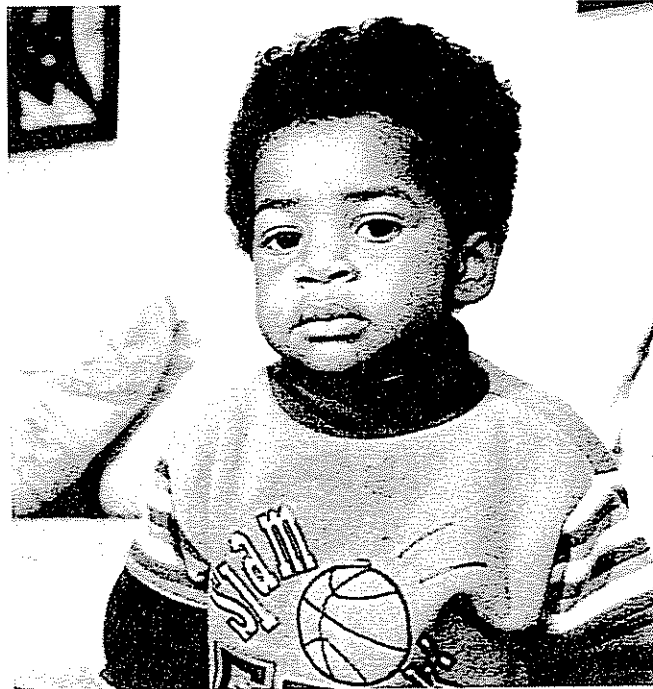
Once your child is referred, your Early Intervention Official will assign an *initial service coordinator* to work with you and your family. The job of your initial service coordinator is to help you with all the steps to your first Individualized Family Service Plan (IFSP).

Your initial service coordinator will start by setting up a time to meet with you to explain the Early Intervention Program. Your initial service coordinator will talk with you about your concerns about your child's development. She or he will:

- Make sure you have a copy of *A Parent's Guide to the Early Intervention Program*.
- Review your family rights and make sure you understand them.
- Talk with you about your child's evaluation for the program.
- Give you the list of evaluators in your county and help you pick one that will meet your child and family needs.
- With your permission, help arrange for your child's evaluation.
- Help you arrange for transportation to your child's evaluation, if you need it.
- Go with you to your child's evaluation if you wish.

If your child's evaluation shows that she or he is eligible for the Early Intervention Program, your initial service coordinator will:

- Set up a meeting to work on your IFSP.
- Help you understand what this meeting will be like, who else must be there, and who can be invited.
- Answer your questions about the Early Intervention Program.



- Explain how your health insurance can be used and that early intervention services will be at no cost to you.
- Help you resolve any problems that might come up—including disagreements about the services you and your child might need.

If the evaluation shows that your child is not eligible for early intervention services, your initial service coordinator will tell you about other services that can help. Or you can appeal the decision (see "Your Rights as a Parent in the Early Intervention Program," page 26, to learn more about appeals).

If you and your initial service coordinator agree that your child needs help right away—before his or her evaluation—you can get services started with an *Interim Individualized Family Service Plan* (interim IFSP). An interim IFSP is possible as long as you and your Early



Intervention Official agree to needed services, your child's evaluation is completed, and an IFSP meeting is held within 45 days of referral.

An Interim Individualized Family Service Plan must include:

- The name of the service coordinator who will be responsible for the interim IFSP
- A physician's or nurse practitioner's order, if needed, for early intervention services in the interim IFSP
- The early intervention services needed immediately and the location, frequency and intensity, and providers of these services.

Interim IFSP

An interim IFSP may be needed when:

- A doctor recommends services begin right away.
- A baby or toddler has trouble feeding (such as poor or no sucking ability) and needs nutrition or therapy services to help.
- Family stress is high, and the child is at risk for out-of-home placement.

Step 3:

Having Your Child Evaluated

If you decide that the Early Intervention Program can help your child, the next step is to have your child *evaluated*. The reasons for the evaluation are to:

- Find out if your child is eligible for early intervention services; and,

- Gather facts about your child's strengths and needs that will help you make good decisions about services.

If your child has a diagnosed disability, she or he will always be eligible for early intervention services. Your child will still need a multidisciplinary evaluation to look at all areas of development and help with the development of an Individualized Family Service Plan (IFSP).

Every child referred to the Early Intervention Program has the right to a free *multidisciplinary evaluation*. *Multidisciplinary* simply means that more than one professional will be a part of your child's evaluation. Your child's evaluation team should have:

- A professional who can look at your child's overall development.
- A professional with special knowledge about your child's problem. For example, if your child is delayed in sitting up, walking, or other motor abilities, a motor therapist might be on your child's team.

Your initial service coordinator will give you a list of evaluators. You have the right to choose any evaluator from this list. Ask your initial service coordinator if you need more information about an evaluator. Your initial service coordinator can give you more details and help you decide on an evaluation team that will be best for your child and family.

Once you pick an evaluator, either you or the initial service coordinator—with your permission—will call the evaluator and make an appointment for your child and family. You, your service coordinator, or your evaluator must tell your Early Intervention Official about your choice.

Checklist of important evaluation information

- Types of professionals that will be on your child's team and an explanation of what they will do.
- How long the evaluation will last.
- Your child's developmental age levels and what that means.
- A diagnosis, if possible.
- Specific areas where your child needs help.
- Explanation of tests—if any—that will be used and what these tests can and cannot tell you about your child's development.
- What the evaluator is looking for in your child's responses.
- What your child does well.
- What your child needs help with, and suggestions about how you can help.
- The types of services that may help your child and family.
- The name of another parent or parent group that can offer support.
- Books, newsletters, magazines, and videos to help you find information about your child's developmental needs.



What is included in the multidisciplinary evaluation?

Your child's multidisciplinary evaluation will include:

- A health assessment, including vision and hearing screening. Your child's health assessment should be done by your child's regular health care provider whenever possible. If your child has had a recent checkup, a new one may not be needed.
- With your permission, a review of any records that may be helpful.
- An assessment of your child's strengths and needs in each area of development (physical, cognitive, communication, social-emotional, and adaptive development).
- An interview with you about your concerns and what your child is like.

The evaluation will be planned to meet the needs of you and your child. The evaluation team may:

- Use a developmental test to look at your child's development.
- Play with your child – or ask you to play with your child.
- Spend some time watching your child.
- Ask you what your child can do now and what he or she can't do yet.

What is a "screening"?

Sometimes a parent or evaluation team may be concerned about a child's development – without being sure why.

A screening can be used to:

- Find out what areas of development – if any – are behind what's expected.
- Help the evaluation team decide what type of evaluation may be best.
- Find out if the child's development is "on target" even though a problem was suspected.

When a screening shows a child's development is "on target," it is unlikely that the child will be eligible for the Early Intervention Program. Parents always have the right to ask for – and get – a full multidisciplinary evaluation for their child (even if a screening suggests a child is developing fine).

You have an important role to play in your child's evaluation. Here's a list of suggestions about ways you can be an active participant in your child's multidisciplinary evaluation:

- You can be an observer.
- You can sit beside or hold your child.
- You can help with activities that explore your child's abilities.
- You can tell team members whether or not what they are seeing is typical of your child.
- You can help the team see your child's strengths and needs.
- You can comfort and support your child.
- You can ask questions and offer your opinions about how your child's evaluation is going.

Choosing an evaluation team

Questions to Ask,

Tips to Think About

- Do you want to have the evaluation at home or at a center? Where do you think your child will do best?
- What time of day is best for your child?
- Is there someone else you would like to have participate in your child's evaluation—a relative, friend, or caregiver—who knows your child well?
- Try to think about your worries and questions before the evaluation. Make a list and bring it to the evaluation.
- Think about your daily routines with your child (eating, sleeping, playing, bathing, etc.). Does anything happen at these times that concerns you? For example, feeding is stressful due to problems with sucking or swallowing.

- The *names* of the professionals who evaluated your child.
- A *description* of what took place at the evaluation. This should include *where* your child was evaluated and *what methods* were used (such as tests or activities).
- Your child's *responses* to the evaluation.
- Your opinion about whether the evaluation showed your child at his or her best.
- The *tests and scores* that were used (if any), and what they mean.

The written and spoken summary of your child's evaluation must be given to you in your language or in the manner you use to communicate, if possible. With your permission, an interpreter can be used to translate your child's evaluation summary.

The evaluation team must complete the written summary as soon as possible after the evaluation. The team must give the summary—and upon request—the full evaluation report to:

- You and your family.
- Your initial service coordinator.
- Your Early Intervention Official (EIO).
- With your permission, your child's doctor.

What happens after an evaluation?

After your child's evaluation, the evaluation team (or a member of the team) will meet with you to share the findings. Make sure your concerns are addressed. Ask questions! Be honest about what you do or don't understand. Tell the evaluation team if you have a different opinion about the findings. The team is responsible for helping you learn what the evaluation means about your child.

The evaluation team must also write an *evaluation report* and *summary*. Your child's evaluation report and summary must include the following information:

- A statement about your child's *eligibility* for the Early Intervention Program.

When more information is needed

Sometimes, parents or service coordinators may feel more information is needed. If you feel a second evaluation is needed, or part of the evaluation should be repeated, you can ask your Early Intervention Official (EIO). You can get a second evaluation (or part of an evaluation) at no cost to you if your Early Intervention Official agrees your child needs one.

Your initial service coordinator may also ask you to permit additional evaluation of your child. Additional evaluation procedures can be done only if you and your Early Intervention Official agree. The evaluation must be at no cost to you.